

# Living With Non-Hodgkin Lymphoma Resource Guide



The First Step to Cancer Survival™

*A Companion Booklet to  
the Cancer Survival Toolbox®  
Non-Hodgkin Lymphoma  
Audio Resource Program*



# The Cancer Survival Toolbox® Program: Non-Hodgkin Lymphoma

The *Cancer Survival Toolbox* (CST) is a FREE set of self-learning audio programs developed by the National Coalition for Cancer Survivorship (NCCS), along with leading cancer organizations. NCCS is the oldest survivor-led cancer advocacy organization in the United States, advocating for quality cancer care for all Americans and empowering cancer survivors to advocate for themselves. To order copies of the *Cancer Survival Toolbox*, call 877-NCCS-YES (877-622-7937) or visit our web site at <http://www.canceradvocacy.org/toolbox>.

The audio program that accompanies this booklet is focused on one type of cancer: non-Hodgkin lymphoma. The goal of this program is to provide you as a person diagnosed with non-Hodgkin lymphoma—as well as your caregivers, family, and friends—with practical tools you can use in your daily life as you deal with your cancer diagnosis and treatment. This program, which was written by cancer survivors and health care professionals, can be helpful both to individuals newly diagnosed with non-Hodgkin lymphoma, as well as to anyone at any other stage of this illness. It can be used on its own or along with the other CST programs.

This module addresses:

- Non-Hodgkin lymphoma diagnosis and basic treatment options
- Side effects and symptom management
- Coping with change
- Information for caregivers

This booklet is offered as a supplement to the non-Hodgkin lymphoma audio program. Contact information for *all* organizations and web sites mentioned in the audio program is provided. Note: Although all resources in this booklet can be helpful to people with cancer, resources developed specifically for people with non-Hodgkin lymphoma are highlighted in gray.

# Table of Contents

What Is Non-Hodgkin Lymphoma?	2
Non-Hodgkin Lymphoma Resources	4
Clinical Trials	6
Coping With Therapy	8
Pain Management	9
Laws Pertaining to Health Insurance	10
Paying for Care	11
Special Resources for Older Persons	12
Death & Dying	13
Suggested Reading Materials	15
Advocacy Organizations & Other Sources of Information	18
Glossary of Common Terms	30
Content Reviewers	33

## Using the Internet to Find Information

In this booklet, a number of Internet resources (web sites) are provided. The Internet allows cancer survivors to get information at the touch of a few keystrokes on a computer in their home, library, or community center.

It can be hard to find your way around the Internet at first. You may need to ask for help. A word of caution: There is a great deal of helpful, reliable, factual information available, but there is also a lot of misinformation. It is important to be sure your sources are reliable and to check information further. The most reliable medical information comes from well-known cancer organizations, research facilities, hospitals, libraries, government agencies, and professional journals. Some of the best sources of information are listed in this booklet.

There are many good books to help you get comfortable with using the Internet. Also, many of the companies that provide Internet access offer free classes to help beginners learn how to use the Internet. Community colleges, senior centers, information specialists in community or hospital libraries, or the cancer information specialist in a cancer resource center may be able to provide some beginning instruction to help you get started.

# What Is Non-Hodgkin Lymphoma?

*Lymphoma* is a term used to describe cancer involving *white blood cells* known as *lymphocytes*. Lymphocytes are part of the body's *immune system*, or what the body uses to fight infection. Lymphoma is the most common type of blood cancer.

There are 2 types of lymphoma:

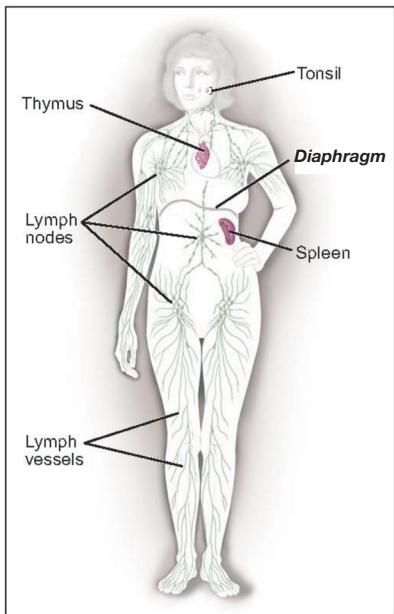
- *Hodgkin lymphoma* (previously known as Hodgkin's lymphoma or Hodgkin's disease), and
- *Non-Hodgkin lymphoma* (NHL; previously known as non-Hodgkin's lymphoma)

Hodgkin lymphoma is the term used to describe a lymphoma that is characterized by the presence of certain types of cells known as *Reed-Sternberg cells*.

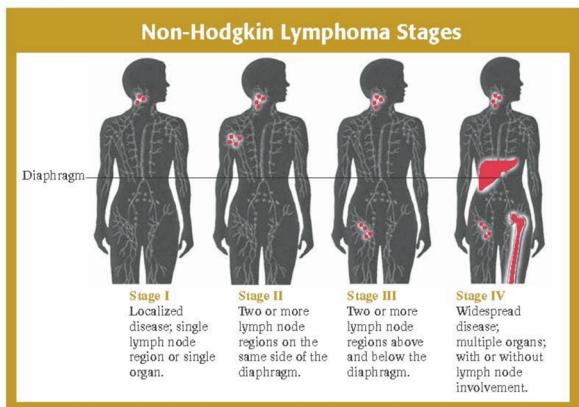
NHL, on the other hand, is a term used to describe all other types of lymphoma. NHL is not one disease, but a group of closely related cancers. More than 60 different types of NHL have been identified. NHL is more common than Hodgkin lymphoma (there are only 6 types of Hodgkin lymphoma). Hodgkin lymphoma and NHL are also different in the way they develop, spread, and are treated.

NHL occurs when the body's white blood cells behave in an abnormal way: for example, when they divide more than they are supposed to, or live longer than they should. Because white blood cells are found throughout the body, NHL can start almost anywhere, including the blood, bone marrow, lymph nodes, or spleen or other organs (Figure 1).

There are 2 types of NHL: *B-cell lymphoma* and *T-cell lymphoma*, named for the different kinds of white blood cells (*B cells* or *T cells*) affected. NHL may be described by stages, or categories; these are described in Figure 2.



**Figure 1:** White blood cells are found throughout the body; because of this, non-Hodgkin lymphoma (NHL) can begin almost anywhere. Pictured here are some common sites where NHL can occur.



**Figure 2: Stages and Categories of Non-Hodgkin Lymphoma.**

From Non-Hodgkin Lymphoma. The Leukemia & Lymphoma Society; 2008.

# Non-Hodgkin Lymphoma Resources

Below are some resources that may be especially helpful to people with non-Hodgkin lymphoma.

## **American Cancer Society**

The American Cancer Society is the nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service.

Phone: 800-ACS-2345

Web Site Address: <http://www.cancer.org>

## **CancerCare**

This national nonprofit organization provides free professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. Programs—including counseling and support groups, education, financial assistance, and practical help—are provided by professional oncology social workers free of charge. In addition, CancerCare offers free telephone workshops for people living with different types of cancer called CancerCare Connect.

Phone: 800-813-HOPE (800-813-4673)

Web Site Address: <http://www.cancercare.org>

(click on “Find Services by Cancer Type” and select “Non-Hodgkin Lymphoma”)

## ***The Leukemia & Lymphoma Society (LLS)***

LLS is the world's largest voluntary health organization dedicated to funding blood cancer research, education, and patient services. The mission of LLS is to cure leukemia, lymphoma, Hodgkin disease, and myeloma and to improve the quality of life of patients and their families.

Phone: 800-955-4572

Web Site Address: <http://www.lls.org>

### ***The Lymphoma Research Foundation (LRF)***

LRF is the nation's largest lymphoma-focused voluntary health organization devoted exclusively to funding lymphoma research and providing patients and health care professionals with critical information on the disease. LRF's mission is to eradicate lymphoma and serve those touched by this disease. LRF also offers webcasts and podcasts for lymphoma patients, survivors, and loved ones.

Phone: 800-500-9976

Web Site Address: <http://www.lymphoma.org>

# Clinical Trials

People with non-Hodgkin lymphoma may be interested in participating in clinical trials. You can get information about clinical trials from members of your cancer care team. They may have individuals already taking part in various trials. The resources listed below also can help people with non-Hodgkin lymphoma and their doctors identify clinical trials that may be of interest.

The clinical trial process for potential new treatment methods involves 4 phases. In phase 1 trials, the goal is to discover harmful side effects. Researchers also try to learn the best way to give new treatments and decide the correct dose. Phase 2 trials are designed to test whether the new treatment is effective against a specific type of cancer. If the phase 2 trial has good results, the treatment method can be tested in phase 3 trials, which compare the new treatment method to the best treatment that is now in use against this particular type of cancer. After new treatment methods have been proven to have benefits over the best standard treatment, the new treatment can be approved by the US Food and Drug Administration (FDA) for general use. Usually, newly FDA-approved treatments are followed in phase 4 trials, also called postmarketing trials, in which problems or concerns with the drug are reported to the FDA and the drug undergoes more testing to assure its effects and overall safety.

The Coalition of Cancer Cooperative Groups (see facing page) suggests asking your doctor these 10 questions if you are thinking of taking part in a clinical trial:

1. Why would this trial be important for me? What is the aim of the study?
2. What are the potential risks and benefits to me compared to other treatment options I have?
3. What are the eligibility requirements?
4. Who will monitor my care and safety?
5. What are the trial's tests and treatments? Will I need to be in the hospital, and if so, how often and for how long?
6. How do the possible side effects of the study treatment compare to side effects of the standard treatment option?
7. What support will be there for me and my caregivers during the trial? Can I talk to someone if I have questions?
8. Will my insurance, Medicaid, Medicare, or managed care plan cover costs of the trial? Who will help me answer these coverage questions?
9. What are my responsibilities and out-of-pocket costs?
10. What is the long-term follow-up care?

## **Clinical Trial Resources**

### ***Coalition of Cancer Cooperative Groups (CCCG)***

CCCG offers clinical trial-matching services. Resources include:

1. Patient and Caregiver Toolkit—a package of practical information and publications you can use to learn about cancer clinical trials. Access this resource at <http://www.cancertrialshelp.org>.
2. A search engine (database) of cancer-related clinical trials. Access this resource at <http://www.cancertrialshelp.org/trialcheck>.

### ***Education Network to Advance Cancer Clinical Trials (ENACCT)***

ENACCT seeks to ensure that everyone affected by cancer is educated about cancer clinical trials.

Phone: 301-562-2774

Web Site Address: <http://www.enacct.org>

### ***Lymphoma Research Foundation (LRF)***

LRF provides a Clinical Trials Information Service to increase awareness about investigational treatments for lymphoma being evaluated at cancer treatment centers nationwide.

Web Site Address:

<http://www.lymphoma.org/site/pp.asp?c=chKOI6PEImE&b=1573731>

### ***National Cancer Institute (NCI)***

Information on cancer trials is available from the NCI.

Phone (NCI's Cancer Information Service [CIS]): 800-4-CANCER (800-422-6237)

Web Site Address: <http://www.cancer.gov>

# Coping With Therapy

These resources may be helpful for people looking for ways to cope with their non-Hodgkin lymphoma therapy.

## ***Sexuality for the Man with Cancer***

The American Cancer Society offers very pertinent information for men with cancer about sex, sexuality, and the impact of a cancer diagnosis. Access this resource at:

Web Site Address:

[http://www.cancer.org/docroot/MIT/MIT\\_7\\_1x\\_SexualityforMenandTheirPartners.asp](http://www.cancer.org/docroot/MIT/MIT_7_1x_SexualityforMenandTheirPartners.asp)

## ***Sexuality for the Woman with Cancer***

The American Cancer Society offers very pertinent information for women with cancer about sex, sexuality, and the impact of a cancer diagnosis. Access this resource at:

Web Site Address:

[http://www.cancer.org/docroot/MIT/MIT\\_7\\_1x\\_SexualityforWomenandTheirPartners.asp](http://www.cancer.org/docroot/MIT/MIT_7_1x_SexualityforWomenandTheirPartners.asp)

## ***Understanding Drug Therapy and Managing Side Effects***

This booklet from the Leukemia & Lymphoma Society of America helps patients understand their drug therapy and how to manage side effects. Access this resource at:

Web Site Address: [http://www.lls.org/all\\_mat\\_req\\_index.adp?b\\_type=2&item\\_id=11203](http://www.lls.org/all_mat_req_index.adp?b_type=2&item_id=11203)

Phone: 800-955-4572

## ***Non-Hodgkin Lymphoma***

This resource from the Leukemia & Lymphoma Society of America provides an overview of NHL as well as information on symptoms, diagnosis, staging, treatment, and side effects of the disease. Access this resource at:

Web Site Address: [http://www.lls.org/attachments/National/br\\_1221745548.pdf](http://www.lls.org/attachments/National/br_1221745548.pdf)

Phone: 800-955-4572

## ***Chemotherapy and You: Support for People With Cancer***

This booklet from the National Cancer Institute explains chemotherapy and how it affects patients with cancer. Access this resource at:

Web Site Address: <https://cissecure.nci.nih.gov/ncipubs/details.asp?pid=34>

Phone: 800-4-CANCER (800-422-6237)

# Pain Management

If you are in pain, seek help. No one needs to suffer unnecessarily. The resources below can help you learn more about pain and pain management.

## *American Chronic Pain Association (ACPA)*

ACPA provides support for persons dealing with chronic pain. There are more than 800 chapters. Find the one closest to you by calling their central number.

Phone: 800-533-3231 or 916-632-0922

Web Site Address: <http://www.theacpa.org>

## *American Pain Foundation (APF)*

APF is dedicated to improving quality of life for people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management.

Phone: 888-615-PAIN (888-615-7246)

Web Site Address: <http://www.painfoundation.org>

## *American Pain Society (APS)*

APS provides a directory of more than 500 pain treatment centers in the United States.

Phone: 847-375-4715

Web Site Address: <http://www.ampainsoc.org>

## *National Hospice and Palliative Care Organization (NHPCO)*

NHPCO's Caring Connections program offers information on understanding pain and guidelines for pain management. Access this resource at:

Web Site Address: <http://www.caringinfo.org/CaringForSomeone/TheTruthAboutPain.htm>

## *Pain Control: Support for People With Cancer*

This brochure can be ordered from the NCI web site. Access this resource at:

Web Site Address: <https://cissecure.nci.nih.gov/ncipubs/details.asp?pid=235>

# Laws Pertaining to Health Insurance

**COBRA**, the *Consolidated Omnibus Budget Reconciliation Act*, gives some workers the right to keep their health insurance coverage for a limited period of time after they leave their jobs. A booklet entitled *Health Benefits Under the Consolidated Omnibus Budget Reconciliation Act* contains detailed information about COBRA and is available online at <http://www.dol.gov/ebsa/pdf/cobraemployee.pdf> or by calling 866-444-EBSA (866-444-3272).

The **Americans with Disabilities Act**, often called the “ADA,” was passed in 1990 and protects workers from job discrimination based on disability or disease. To file a complaint under the ADA, call the Equal Employment Opportunity Commission (EEOC) to obtain the location of your regional EEOC office in order to file a complaint. The number is 800-669-4000.

**ERISA**, the federal **Employee Retirement Income Security Act**, is the nation’s major pension law and provides rights and protections for private pension and health benefit plan participants and their beneficiaries. ERISA prohibits an employer from discriminating against an employee for the purposes of preventing the employee from collecting benefits under an employee benefit plan.

The **Family and Medical Leave Act** requires an employer to provide an employee with the same or similar job in the event the employee needs to take an unpaid leave of absence. This law lets eligible employees take up to 12 weeks of leave for certain family or medical reasons. Employers with 50 or more employees within 75 miles of the workplace are covered by the Act. To file a complaint under the Family and Medical Leave Act, contact the Employment Standards Administration, Wage and Hour Division, of the US Department of Labor. A regional office will be listed in your telephone book under “United States Government.”

The **Health Insurance Portability and Accountability Act (HIPAA)** protects many workers from discrimination based on preexisting medical conditions and other health-related factors. This law protects employees from losing their insurance when they change jobs or move to a different state. HIPAA helps some employees keep their health insurance when they change jobs. It does not prevent increases in premiums associated with a new group plan or when the insured person moves to a new location.

## Paying for Care

If you don't have insurance, get help through a social worker and/or a financial counselor at your local hospital or cancer treatment center. The case manager will contact you and begin working with you to assure that your questions are answered and your needs are met. Ask your case manager for his or her direct-dial telephone extension so you can avoid time-consuming menu selections and recordings when you call the case manager in the future.

For more financial assistance options, you can also refer to the *Cancer Survival Toolbox* program *Finding Ways to Pay for Care*. In addition, please refer to The Wellness Community resource *Frankly Speaking About Cancer: Coping with the Cost of Care*. The Patient Advocate Foundation web site, <http://patientadvocate.org>, and the CancerCare web site, <http://www.cancercare.org>, also offer information and assistance.

# Special Resources for Older Persons

The following resources may be of interest to older persons dealing with non-Hodgkin lymphoma.

## *American Geriatrics Society*

The Empire State Building  
350 Fifth Avenue, Suite 801  
New York, NY 10118  
Phone: 212-308-1414  
Web Site Address: <http://www.americangeriatrics.org>

## *Questions and Answers When Looking for an Elder Law Attorney*

This pamphlet covers issues such as where to find an attorney, what questions to ask, and how to discuss fees and more. To obtain a copy, send a self-addressed, stamped envelope (legal size) to:

National Academy of Elder Law Attorneys  
1604 North Country Club Road  
Tucson, AZ 85716  
Phone: 520-881-4005  
Web Site Address: <http://www.naela.com>

## *Shape Your Health Care Future with Health Care Advance Directives*

This pamphlet is available through the American Bar Association (ABA) web site.  
Access this resource at:

Phone: 202-662-1000 or 800-285-2221  
Web Site Address: [http://www.abanet.org/aging/publications/docs/shape\\_your.pdf](http://www.abanet.org/aging/publications/docs/shape_your.pdf)

# Death & Dying

Unlike 20 years ago, when cancer and grief were both kept hidden, there is now a great deal of information to help you and your loved ones learn about your choices and resources. The *Basic Skills* of the Toolbox—communicating, finding information, decision-making, problem-solving, negotiating, and standing up for your rights—can be used at every step of the journey.

The resources listed below may be helpful for people with advanced illness.

## *Aging With Dignity and Five Wishes®*

PO Box 1661

Tallahassee, FL 32302-1661

Phone: 888-5WISHES (888-594-7437)

Web Site Address:

<http://www.agingwithdignity.org>

## *American Association of Retired Persons (AARP)*

Web Site Address: <http://www.aarp.org>

## *American Foundation for Suicide Prevention (AFSP)*

Phone: 888-333-AFSP (888-333-2377)  
or 212-363-3500

Web Site Address: <http://www.afsp.org>

## *American Pain Foundation (APF)*

Web Site Address:

<http://www.painfoundation.org>

## *Association of Oncology Social Work (AOSW)*

Web Site Address: <http://www.aosw.org>

## *CancerCare*

Web Site Address:

<http://www.cancercare.org>

## *Candlelighter's Childhood Cancer Foundation*

Web Site Address:

<http://www.candlelighters.org>

## *Children's Hospice and Palliative Care Coalition*

Web Site Address:

<http://www.childrenshospice.org>

## *Compassion & Choices*

Web Site Address:

<http://www.compassionandchoices.org>

## *The Compassionate Friends*

Phone: 877-969-0010

Web Site Address:

<http://www.compassionatefriends.org>

## *Elisabeth Kübler-Ross (EKR) Foundation*

Web Site Address:

<http://www.elisabethkublerross.com>

## *Hospice and Palliative Nurses Foundation (HPNF)*

Web Site Address: <http://www.hpnf.org>

# Death & Dying

## *Hospice Foundation of America (HFA)*

Web Site Address:

<http://www.hospicefoundation.org>

## *National Association of Social Workers (NASW)*

NASW online courses on cancer, cancer caregiving, and end-of-life care for consumers and professionals can be accessed at <http://www.naswweb.org>. NASW also offers “Understanding End of Life Care,” an online course for individuals and their loved ones affected by death and dying. The course is available at:

<http://helpstartshere.org/>  
UnderstandingEndofLifeCareCourse/  
tabid/169/language/en-US/Default.aspx

Web Site Addresses:

<http://www.socialworkers.org>  
<http://www.helpstartshere.org>

## *National Cancer Institute (NCI)*

Web Site Address:

<http://www.cancer.gov/cancertopics/support>

## *National Center for Grieving Children and Families (The Dougy Center)*

Web Site Address:

<http://www.grievingchild.org>

## *National Coalition for Cancer Survivorship (NCCS)*

NCCS offers an audio program titled “Dying Well—The Final Stage of Survivorship” in the *Cancer Survival Toolbox*. Access this resource at:

Web Site Address:

<http://www.canceradvocacy.org/toolbox/>

## *National Hospice and Palliative Care Organization (NHPCO)*

Web Site Addresses:

<http://www.nhpco.org>  
<http://www.caringconnections.org>

## *National Social Worker Finder*

Web Site Address:

<http://www.helppro.com/nasw>

## *On Our Own Terms: Moyers on Dying*

Available at:

Web Site Address:  
<http://www.pbs.org/wnet/onourownterms>

## *Pathways: Education & Consultation in End of Life Care*

Phone: 520-400-0274

Web Site Address:  
<http://www.pathwayseol.com>

## *Reflections: A Guide to End of Life Issues for You and Your Family*

Written by Roger C. Bone, MD, a physician dying from renal cancer, this 60-page booklet covers many important issues about planning for end-of-life care. It is available free and can be downloaded from the Kidney Cancer Association’s web site below.

Kidney Cancer Association

1234 Sherman Avenue, Suite 203  
Evanston, IL 60202-1375

Phone: 800-850-9132

Web Site Address: <http://kidneycancer.org>

# Suggested Reading Materials

The following is a list of materials designed to help cancer survivors, including people with non-Hodgkin lymphoma.

## **Support for Cancer Survivors**

Materials published by the National Coalition for Cancer Survivorship are available at <http://www.canceradvocacy.org>.

Ackermann A, Ackermann A. (2002). *Our Mom Has Cancer*. Atlanta, GA: American Cancer Society.

Adler E. (2005). *Living with Lymphoma*. Baltimore, MD: Johns Hopkins University Press.

Blogger.com. Available at <http://www.blogger.com>.

Calder KJ, Pollitz K. (2006). *What Cancer Survivors Need to Know About Health Insurance*. Silver Spring, MD: National Coalition for Cancer Survivorship. Sixth Edition.

Clark EJ (ed). (2006). *Teamwork: The Cancer Patient's Guide to Talking With Your Doctor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fourth Edition. 58pp.

Clark EJ. (2007). *You Have the Right to Be Hopeful*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fourth Edition.

*Coping® With Cancer* magazine. PO Box 682268, Franklin, TN 37068-2268.

*CURE: Cancer Updates, Research, & Education* magazine. Available at <http://www.curetoday.com> or 800-210-CURE (800-210-2873).

Feuerstein M, Findley P. (2006). *The Cancer Survivor's Guide: The Essential Handbook to Life After Cancer*. New York, NY: Marlowe & Company.

Fincannon J, Bruss K. (2002). *Couples Confronting Cancer: Keeping Your Relationship Strong*. Atlanta, GA: American Cancer Society.

Greenfield NR. (2004). *When Mommy Had a Mastectomy*. Savage, MD: Bartleby Press.

Gruman J. (2007). *AfterShock: What to Do When the Doctor Gives You—or Someone You Love—a Devastating Diagnosis*. New York, NY: Walker and Company.

# Suggested Reading Materials

## Wendy Harpham Web Site

Dr. Harpham is a doctor of internal medicine, best-selling author, and long-term cancer survivor. She was diagnosed with non-Hodgkin lymphoma in 1990 and works tirelessly to educate, comfort, and inspire patients.

Web Site Address: <http://www.wendyharpham.com/>

## Wendy Harpham Blog

Web Site Address: <http://wendyharpham.typepad.com/>

Harpham WS. (2003). *Diagnosis: Cancer. Your Guide Through the First Few Months of Healthy Survivorship*. New York, NY: W.W. Norton & Company. Third Edition.

Harpham WS. (2004). *When a Parent Has Cancer: A Guide to Caring for Your Children*. New York, NY: HarperCollins.

Harpham WS. (2005). *Happiness in a Storm: Facing Illness and Embracing Life as a Healthy Survivor*. New York, NY: W.W. Norton & Company.

Hoffman B (ed). (2007). *Working It Out: Your Employment Rights as a Cancer Survivor*. Silver Spring, MD: National Coalition for Cancer Survivorship.

Hoffman B (ed). (2004). *A Cancer Survivor's Almanac: Charting Your Journey*. National Coalition for Cancer Survivorship. Hoboken, NJ: John Wiley & Sons. Third Edition.

Houts P, Bucher J. (2001). *Caregiving: A Step-By-Step Resource for Caring for the Person with Cancer at Home*. Atlanta, GA: American Cancer Society.

*Self-Advocacy: A Cancer Survivor's Handbook*. (2003). Silver Spring, MD: National Coalition for Cancer Survivorship. First Edition. 26pp.

*The Prescription for Living Plan*. Available at:  
<http://www.nursingcenter.com/ajncancersurvivors>.

## **Support for Caregivers**

National Coalition for Cancer Survivorship. (2009). *Caring for the Caregiver*. Available at: <http://www.canceradvocacy.org/toolbox/10-caring-for-the-caregiver> or 877-NCCS-YES (877-622-7937).

National Institutes of Health, National Cancer Institute. (2007). *Caring for the Caregiver: Support for Cancer Caregivers*. Available at: <http://www.cancer.gov> or 800-4-CANCER (800-422-6237).

National Institutes of Health, National Cancer Institute. (2005). *When Someone You Love Is Being Treated for Cancer*. Available at: <http://www.cancer.gov> or 800-4-CANCER (800-422-6237).

National Institutes of Health, National Cancer Institute. (2003). *Taking Time: Support for People With Cancer and the People Who Care About Them*. Available at: <http://www.cancer.gov> or 800-4-CANCER (800-422-6237).

# Advocacy Organizations & Other Sources of Information

The National Cancer Institute's Cancer Information Service (CIS), nongovernmental organizations such as the American Cancer Society, and cancer type-specific organizations like the Leukemia & Lymphoma Society provide up-to-date information and connections to other people with the same kind of cancer. Some grassroots advocacy groups also facilitate support.

Important telephone numbers, mailing addresses, and Internet addresses mentioned throughout the entire Toolbox audio program are listed below. For additional resources, please visit the Toolbox web site at <http://www.canceradvocacy.org/toolbox> or visit <http://www.canceradvocacy.org/resources/guide>.

## **AARP**

This organization provides various resources on issues of caregiving such as long-term financing, home care, housing options, video and written resources, and an online weekly caregiver support group.

Phone: 888-OUR-AARP (888-687-2277)

Web Site Address: <http://www.aarp.org/families/caregiving>

## **Alliance for Aging Research**

The Alliance promotes research to improve quality of life for a growing population of older persons. It also provides educational programs for consumers and professionals

Phone: 202-293-2856

Web Site Address: <http://www.agingresearch.org>

## **American Association for Geriatric Psychiatry (AAGP)**

AAGP provides referrals for geriatric psychiatrists. Written materials for patients, family members, and caregivers may also be obtained.

Phone: 301-654-7850

Web Site Address: <http://www.aagpgpa.org>

## *American Association of Sexuality Educators, Counselors, and Therapists (AASECT)*

AASECT is devoted to the promotion of sexual health by the development and advancement of the fields of sex therapy, counseling, and education. Their web site can help you locate a sexuality educator, counselor, or therapist in your area.

Phone: 804-752-0026

Web Site Address: <http://www.aasect.org>

## *American Cancer Society (ACS)*

ACS provides written information about cancer, cancer research, and treatment options. Call to locate a chapter near you and learn about what programs and resources are being offered, including the Patient Navigator Program.

Phone: 800-ACS-2345 (800-227-2345)

Web Site Address: <http://www.cancer.org>

## *American Chronic Pain Association (ACPA)*

ACPA provides support for persons dealing with chronic pain. There are more than 800 chapters, and you may find the one closest to you by calling their central number.

Phone: 800-533-3231 or 916-632-0922

Web Site Address: <http://www.theacpa.org>

## *American Pain Foundation (APF)*

APF is dedicated to improving quality of life for people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management.

Phone: 888-615-PAIN (888-615-7246)

Web Site Address: <http://www.painfoundation.org>

## *American Pain Society (APS)*

APS provides a directory of more than 500 pain-treatment centers in the United States.

Phone: 847-375-4715

Web Site Address: <http://www.ampainsoc.org>

# Advocacy Organizations & Other Sources of Information

## *America's Health Insurance Plans (AHIP)*

AHIP is the national association representing nearly 1,300 member companies providing health insurance coverage to more than 200 million Americans. Their web site provides consumer information about private insurance, managed care, getting coverage, and answers to frequently asked questions.

601 Pennsylvania Avenue, NW

South Building, Suite 500

Washington, DC 20004

Phone: 202-778-3200

Web Site Address: <http://www.ahip.org>

## *Association of Oncology Social Work (AOSW)*

AOSW is an organization of oncology social workers and others who specialize in helping cancer survivors and their families with the emotional and practical impact of cancer.

100 North 20th Street, 4th Floor

Philadelphia, PA 19103

Phone: 215-599-6093

Web Site Address: <http://www.aosw.org>

## *BBB Wise Giving Alliance*

This group, a service of the Better Business Bureau, offers information on legitimate charities and causes.

Phone: 703-276-0100

Web Site Address: <http://www.bbb.org/us/charity/>

## *CancerCare*

This is a national organization that provides a toll-free counseling line and educational programs. Counseling and some materials are also available in Spanish. All services are free of charge.

Phone: 800-813-HOPE (800-813-4673)

Web Site Address: <http://www.cancercare.org>

### **Cancer.net**

This patient education web site from the American Society of Clinical Oncology (ASCO) provides information on more than 50 types of cancer and their treatments, clinical trials, side effects, and coping. It also includes live chats, message boards, and links to support groups.

Phone: 888-651-3038

Web Site Address: <http://www.cancer.net>

### ***Cancer Survivor's Treatment Record: Taking Care of Yourself for Life***

This booklet by Kathy Ruccione and Wendy Hobbie will help you keep track of your medical history with a summary of your cancer treatment and guidelines for health monitoring that may reduce your chances of medical problems in the future. Available for download at [http://childhoodcancerguides.org/treatment\\_record.pdf](http://childhoodcancerguides.org/treatment_record.pdf).

### **Caregivers Media Group**

This organization provides an online newsletter, workshops, audiotapes, and information on caregivers and the work force, caregiver tips, and other topics.

Phone: 800-829-2734

Web Site Address: <http://www.caregiver.com>

### **Consumer Action**

You may download a 30-page booklet, *It's Your Choice: Are Medicare HMOs right for you?*, written with assistance from the Gray Panthers and the National Consumers League. The brochure, available in English and Spanish, advises people currently on Medicare about changes taking place in Medicare and what they mean.

221 Main Street, Suite 480

San Francisco, CA 94105

Phone: 415-777-9635

Web Site Address: <http://www.consumer-action.org>

# Advocacy Organizations & Other Sources of Information

## *Eldercare Locator*

This nationwide, directory-assistance service is designed to help older persons and caregivers locate local support resources. Eldercare Locator links you with state and local area agencies on aging, where you can get information about services such as transportation, meals, home care, housing alternatives, legal issues, and social activities. You may visit their web site or call the toll-free number weekdays from 9 AM until 8 PM eastern time.

Phone: 800-677-1116

Web Site Address: <http://www.eldercare.gov>

## *Family Caregiver Alliance (FCA)*

FCA provides a clearinghouse that covers current medical, social, public policy, and caregiving issues related to brain impairments of adults, including brain tumors. Information is also available in Spanish and Chinese.

Phone: 800-445-8106

Web Site Address: <http://www.caregiver.org>

## *Gerontological Society of America (GSA)*

GSA is an organization for professionals in the field of aging. GSA focuses on promoting the scientific study of aging. It provides reports, bibliographic searches (\$5 per keyword), publications, and a list of online resources useful to older persons with cancer and their caregivers.

1220 L Street NW, Suite 901

Washington, DC 20005

Phone: 202-842-1275

Web Site Address: <http://www.geron.org>

### ***Health Insurance Counseling and Advocacy Program (HICAP)***

HICAP is a national Medicare assistance program for the elderly and disabled. HICAP helps people learn about Medicare benefits including Medicare HMOs, long-term care, Medicare supplemental or long-term care insurance, and other important changes in Medicare.

Web Site Address: <http://www.inlandagency.org/hicap.html>

### ***Health Privacy Project (HPP)***

HPP is a nonprofit organization that was founded to raise public awareness of the importance of ensuring health privacy to improve health care quality and access.

Web Site Address: <http://www.healthprivacy.org>

### ***Hospice Foundation of America (HFA)***

HFA provides general information about hospices and will assist you in locating a hospice near you.

Phone: 800-854-3402

Web Site Address: <http://www.hospicefoundation.org>

### ***Impotence Specialists.com***

This web site can help you find a physician in your area and offers information about treatment options.

Web Site Address: <http://www.impotencespecialists.com>

### ***Intercultural Cancer Council (ICC)***

ICC works to eliminate the unequal burden of cancer in racial and ethnic minorities and medically underserved populations. This organization offers a wide variety of educational programs.

Phone: 713-798-4617

Web Site Address: <http://www.iccnetwork.org>

# Advocacy Organizations & Other Sources of Information

## *Journey Forward*

Journey Forward is a new program for doctors and their patients who have recently completed active treatment for cancer. This program was created by a unique collaboration of organizations with the common goal of improving survivorship care. Journey Forward promotes the use of a Survivorship Care Plan. This plan, completed by the survivor's oncology team, gives clear steps for care after active treatment.

Phone: 707-636-5900 (9 AM-5 PM, PST/PDT)

Web Site Address: <http://www.journeyforward.org>

## *Lance Armstrong Foundation (LAF)*

LAF seeks to promote the optimal physical, psychological, and social recovery and care of cancer survivors and their loved ones. The LAF web site, Livestrong.org, focuses on the physical, emotional, and practical issues that you may encounter after completing active treatment for cancer. The site features real survivors discussing their experiences as well as links to more information.

Phone: 866-467-7205

Web Site Address: <http://www.livestrong.org>

## ***Leukemia & Lymphoma Society of America (LLS)***

LLS provides support services, including local support groups and financial assistance, to persons with leukemia, lymphoma, multiple myeloma, and non-Hodgkin lymphoma.

Phone: 800-955-4LSA (800-955-4572)

Web Site Address: <http://www.lls.org>

## *Life Insurance Settlement Association (LISA)*

This association can provide you with a list of viatical companies that will buy your life insurance policies under certain conditions.

Phone: 407-894-3797

Web Site Address: <http://www.thevoiceoftheindustry.com/>

## ***Medicare***

This US government agency provides various services in English and Spanish, including publications on Medicare health plans and Medicare managed care choices. Some publications are also available in Braille or audio format for the visually impaired.

Phone: 800-MEDICARE (800-633-4227)

Web Site Address: <http://www.medicare.gov>

## ***National Association of Community Health Centers, Inc.***

This organization provides a listing of local nonprofit, community-owned health care programs serving low income and medically underserved urban and rural communities.

Phone: 301-347-0400

Web Site Address: <http://www.nachc.com>

## ***National Association of Social Workers (NASW)***

NASW, the largest membership association of social workers nationwide, provides a consumer web site with information and advice regarding health, mental health, cancer, and other illnesses, as well as a way to find a social worker near you.

750 First Street, NE, Suite 700

Washington, DC 20002-4241

Phone: 202-408-8600

Web Site Addresses:

<http://www.socialworkers.org>

<http://www.helpstartshere.org>

## ***National Cancer Institute (NCI)***

NCI offers many educational resources for cancer survivors, including the Cancer Information Service (CIS), a network of regional offices providing easy-to-understand information in English and Spanish on cancer treatment, research, and local cancer-related services and community resources. The NCI web site features information about clinical trials as well as *Facing Forward Series: Life After Cancer Treatment*.

Phone: 800-4-CANCER (800-422-6237)

Web Site Address: <http://www.cancer.gov>

# Advocacy Organizations & Other Sources of Information

## ***National Coalition for Cancer Survivorship (NCCS)***

NCCS advocates for quality cancer care for all Americans and provides tools that empower people affected by cancer to advocate for themselves. Founded by and for cancer survivors in 1986, NCCS created the widely accepted definition of survivorship and considers someone a cancer survivor from the time of diagnosis through the balance of life. Its free publications and resources include the award-winning *Cancer Survival Toolbox®*, a self-learning audio program created by leading cancer organizations to help people develop essential skills to meet the challenges of their illness.

1010 Wayne Avenue, Suite 770

Silver Spring, MD 20910-5600

Phone: 877-NCCS-YES (877-622-7937)

Web Site Addresses:

<http://www.canceradvocacy.org>

<http://www.canceradvocacynow.org>

<http://www.canceradvocacy.org/toolbox>

## ***National Family Caregivers Association (NFCA)***

NFCA advocates on behalf of caregivers. Their services include education, information, support, public awareness, and advocacy.

Phone: 800-896-3650

Web Site Address: <http://www.nfcacares.org>

## ***National Hospice and Palliative Care Organization (NHPCO)***

NHPCO can assist you in finding a hospice; it also provides consumer-oriented materials through its consumer-focused web site, Caring Connections.

Phone: 800-658-8898

Web Site Addresses:

<http://www.nhpco.org>

<http://www.caringinfo.org>

### ***National Institute on Aging (NIA)***

NIA is dedicated to research, education, training, information, and referral. This organization provides a broad range of written materials on various topics. Phone: 800-222-2225 or 800-222-4225 (TTY)  
Web Site Address: <http://www.nia.nih.gov>

### ***National Marrow Donor Program (NMDP)***

NMDP works to ensure that every patient has the best possible chance to receive the transplant he or she needs.

Phone: 800-627-7692  
Web Site Address: <http://www.marlow.org>

### ***Needy Meds, Inc.***

This is a clearinghouse for information about getting medications from pharmaceutical companies. There is no charge for the service.

PO Box 219  
Gloucester, MA 01931  
Web Site Address: <http://www.needymeds.com>

### ***Office of Minority Health Resource Center (OMHRC)***

OMHRC provides health information regarding Native American, Alaska Native, African American, Asian American, Pacific Islander, and Hispanic/Latino populations.

PO Box 37337  
Washington, DC 20013-7337  
Phone: 800-444-6472  
Web Site Address: <http://www.omhrc.gov>

# Advocacy Organizations & Other Sources of Information

## ***OncoLink***

OncoLink, managed by the Abramson Cancer Center of the University of Pennsylvania, provides a wide range of cancer-related information. It includes information on clinical trials, reimbursement assistance programs, and a caregiver education course.

Web Site Address: <http://www.oncolink.upenn.edu>

## ***Oncology Nursing Society (ONS)***

This national organization is composed of more than 35,000 registered nurses and other health care providers who work with persons who have cancer. Their web site has a special section for patient information and educational resources.

125 Enterprise Drive  
RIDC Park West  
Pittsburgh, PA 15275-1214  
Phone: 866-257-4ONS (866-257-4667)  
Web Site Address: <http://www.ons.org>

## ***Partnership for Prescription Assistance (PPA)***

PPA helps qualifying patients who lack prescription coverage to access public and/or private programs.

Phone: 888-4PPA-NOW (888-477-2669)  
Web Site Address: <http://www.pparx.org>

## ***Social Security Administration (SSA)***

The Social Security Administration of the federal government manages Social Security, Supplemental Security Income, Medicare, and parts of Medicaid.

Phone: 800-772-1213  
Web Site Address: <http://www.ssa.gov>

## ***US Department of Labor Employee Benefits Security Administration***

You may order a free copy of a publication, *Protect Your Pension: A Quick Reference Guide*, that provides information about safeguarding your pension plan.

200 Constitution Avenue, NW, Suite N-5625  
Washington, DC 20210  
Phone: 866-444-3272 or 877-889-5627 (TTY)  
Web Site Address: <http://www.dol.gov/ebsa>

### ***Veterans Affairs***

Veterans can consult with a VA benefits counselor at any VA Medical Center, or call the Department of Federal Benefits.

Phone: 800-827-1000

Web Site Address: <http://www.va.gov>

### ***Well Spouse Association***

This association provides a quarterly newsletter, pamphlets, mutual aid support groups in many areas, letter-writing support groups, an annual conference, and regional and weekend meetings around the country for caregivers.

Phone: 800-838-0879

Web Site Address: <http://www.wellspouse.org>

### ***The Wellness Community (TWC)***

TWC is a national nonprofit organization dedicated to providing free emotional support, education, and hope for people with cancer and their loved ones. Through participation in professionally led support groups, educational workshops, and mind/body programs utilizing the Patient Active Concept, people affected by cancer can learn vital skills to regain control, reduce feelings of isolation, and restore hope—regardless of the stage of disease. All programs are free of charge.

Phone: 888-793-WELL (888-793-9355)

Web Site Address: <http://www.thewellnesscommunity.org>

# Glossary of Common Terms

**Aggressive lymphoma:** a type of lymphoma that grows and spreads quickly, and has severe symptoms; it is seen frequently in patients who are HIV-positive (AIDS-related lymphoma); also called intermediate-grade lymphoma or high-grade lymphoma

**Allogeneic stem cell transplantation:** a procedure in which a person receives blood-forming stem cells (cells from which all blood cells develop) from a genetically similar, but not identical, donor; this is often a sister or brother, but could be an unrelated donor

**Anemia:** A condition in which the number of red blood cells is below normal

**Autologous stem cell transplantation:** a procedure in which a person's stem cells (cells from which all blood cells develop) are removed, stored, and later given back to the same person

**B cell:** a white blood cell that comes from bone marrow; as part of the immune system, B cells make antibodies and help fight infections; also called B lymphocyte

**B-cell lymphoma:** a term used to describe a type of lymphoma involving white blood cells known as B cells

**Benign:** a term used to describe a swelling or growth that is not cancerous, that does not spread from one part of the body to another, and which is usually not life-threatening

**Biological therapy:** treatment to boost or restore the ability of the immune system to fight cancer, infections, and other diseases and to lessen certain side effects that may be caused by some cancer treatments; also called immunotherapy, biotherapy, or biological response modifier therapy (BRM therapy); agents used in biological therapy include monoclonal antibodies, growth factors, and vaccines; these agents may also have a direct antitumor effect

**Biopsy:** a procedure where a piece of tissue or fluid (a group of cells) is taken from a person's body and examined with a microscope to see if the cells are normal or not; a biopsy is a common way of determining if a person has cancer and, if so, what type it is

**Blood transfusion:** the administration of blood or blood products into a blood vessel

**Bone marrow:** the soft, sponge-like tissue in the center of most bones that produces white blood cells, red blood cells, and platelets

**Diffuse large B-cell lymphoma:** a type of B-cell non-Hodgkin lymphoma (cancer of the immune system) that is usually aggressive (fast-growing); it is the most common type of non-Hodgkin lymphoma and is marked by rapidly growing tumors in the lymph nodes, spleen, liver, bone marrow, or other organs; other symptoms include fever, night sweats, and weight loss; there are several subtypes of diffuse large B-cell lymphoma

**Follicular lymphoma:** a type of B-cell non-Hodgkin lymphoma (cancer of the immune system) that is usually indolent (slow-growing); the tumor cells grow as groups to form nodules; there are several subtypes of follicular lymphoma

**Grade (grading):** a system used to categorize how quickly a tumor is likely to grow and spread; the grade of a tumor depends on how abnormal the cancer cells look under a microscope; grading systems are different for each type of cancer

**Hematologic cancer:** a cancer affecting blood-forming cells in the bone marrow, such as leukemia and non-Hodgkin lymphoma

**Hodgkin lymphoma (previously known as Hodgkin's lymphoma or Hodgkin's disease):** a cancer that affects certain types of white blood cells known as lymphocytes; the disease is characterized by the presence of Reed-Sternberg cells; 6 types of Hodgkin lymphoma have been identified

**Immune system:** the system of cells, tissues, and organs the body uses to fight infection

**Indolent lymphoma:** a type of lymphoma that tends to grow and spread slowly and has few symptoms; also called low-grade lymphoma

**Low-grade lymphoma:** a type of lymphoma that tends to grow and spread slowly and has few symptoms; also called indolent lymphoma

**Lymphocytes:** a type of white blood cell; lymphocytes are part of the body's immune system, or what the body uses to fight infection; cancer involving lymphocytes is known as lymphoma

**Lymphoma:** a type of cancer that starts in a lymph node

**Malignant:** a term used to describe a type of tumor that is cancerous

**Metastasis:** (a) the spread of cancer cells from the original tumor through the bloodstream and lymphatic system to another part of the body; (b) a secondary tumor caused by this movement of cancer cells

**Neoplasm:** a new growth of cells

**Noncontiguous lymphoma:** lymphoma in which the lymph nodes containing cancer are not next to each other but are on the same side of the diaphragm (the thin muscle below the lungs that helps breathing and separates the chest from the abdomen)

**Non-Hodgkin lymphoma (previously known as non-Hodgkin's lymphoma):** a term used to describe all types of lymphoma that are not characterized by the presence of Reed-Sternberg cells; more than 60 types of non-Hodgkin lymphoma have been identified

# Glossary of Common Terms

**Prognosis:** a prediction of what might happen to an individual in a specific case of a disease

**Prognostic indicators:** a situation, condition, or characteristic that can be used to estimate the chance of recovery from a disease or the chance of the disease recurring (coming back)

**Reed-Sternberg cells:** the cells that are present in individuals with Hodgkin lymphoma

**Site of origin:** the part of the body where a cancer started

**Solid tumor:** a firm, compact tumor made up of a cluster of cells

**Stem cell transplantation:** a method of replacing immature blood-forming cells that were destroyed by cancer treatment; the stem cells are given to the person after treatment to help the bone marrow recover and continue producing healthy blood cells

**Stage (staging):** a system used to define the extent of spread of a cancer

The stage of cancer is defined by 3 factors: (1) how large the tumor (T) itself is; (2) how much, if any, the tumor has spread to nearby lymph nodes (N); and (3) whether there is any known metastasis (M) or spread to distant organs. Stage 0 means an *in situ* carcinoma—a tumor that has not spread to nearby tissues and is unlikely to have migrated or metastasized to lymph nodes or other organs. The TNM status for an *in situ* carcinoma would be T0 N0 M0—a very small tumor, with no lymph node involvement and no evidence of metastasis. A non-small-cell lung cancer that is larger than 3 centimeters (about 1½ inches) in diameter, with spread to the lymph nodes around the bronchus but none to other distant organs, would be staged as T2 N1 M0.

**T cells:** white blood cells that mature in the thymus; T cells target infections and trigger greater immune response; also called T lymphocytes

**T-cell lymphoma:** a term used to describe a type of lymphoma that affects the white blood cells known as T cells

**Tumor margin:** the edge or border of the tissue removed in cancer surgery; described as negative or clean when the pathologist finds no cancer cells at the edge of the tissue, suggesting that all of the cancer has been removed; described as positive or involved when the pathologist finds cancer cells at the edge of the tissue, suggesting that all of the cancer has not been removed

**White blood cells:** infection-fighting cells, including neutrophils and monocytes (which ingest germs), and lymphocytes (which produce antibodies as an immune response to an infection)

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Did you find this program useful? Your feedback will help us provide the best information to people with non-Hodgkin lymphoma. Please take the enclosed survey, fill it out online at <http://www.canceradvocacy.org/toolbox/hema/survey>, or call **877.NCCS-YES (877-622-7937)**.

# Living With Non-Hodgkin Lymphoma Resource Guide



The First Step to Cancer Survival™

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